

WHAT'S NEW at CHIPP?

****A special update for people interested in health information for policy in California****
December 6, 1996

For many of our readers, it has been a while since you signed up on the mailing list to receive project updates for the California Health Information for Policy Project. Despite how busy we were this year, a few of the activities planned for 1996 had to be delayed. One of them was our project updates via email. When CHIPP's web page was established in October of 1995, one of the intended goals was to email periodic updates on CHIPP activities to interested people visiting our web site. Since it is difficult to know in advance what has changed on our web site since your last visit, this email update will focus readers on areas of interest and save time. In the report that follows, we would like to update you on the status of activities and provide a window into what we are planning down the road. This communication is sent in plain text format to accommodate the great variety of potential servers and email software you may be using.

First off, we are pleased with the wide variety of people who have visited our site. Since the first person responded on December 7, 1995, we have received about 300 inquiries from people who want to be on the mailing list. It is exciting to see such wide interest in health information and policy from so many market sectors--research institutions, all levels of government, universities, non-profits, for-profits, corporations, students, consultants, and private citizens. The geographic distribution of our visitors is fantastic also! Communications originate from all over the world--Berlin, Russia, Portugal, Paris, New Zealand, and nearly every state in the U.S., thanks to the great technology the Internet brings to business offices and home desk tops. Listed below are summaries of our most exciting activities.

NEW HEALTH DATA BASE IS CREATED BY LINKING FILES

CHIPP recently completed a major project successfully linking the 1992 California Vital Statistics Birth/Infant Death Cohort File, containing over 600,000 annual births, with the California Hospital Patient Discharge Data maternal and infant records. This linkage produced a sizeable new public file that offers medical researchers an insightful new resource for perinatal outcomes studies. The linkage was performed with approximately a 98% record linkage rate using primary variables that are common to the two data sets--birth hospital, birth date, sex, delivery mode, zip code of residence, payor source, and race/ethnicity--and secondary health status information to optimize the likelihood of linking low birth weight or premature infants in one database to infants of similar health status in the other while randomizing cases in which no secondary information is present. The resulting data set combines information on a neonate's socio-demographic characteristics, prenatal care, and mortality aspects and connects it to detailed health outcome and resource utilization data, thus establishing an extensive database for epidemiological studies.

A major goal of the linkage project was to establish a reliable methodology for linking these files in subsequent years. Although the project used the 1992 Birth Cohort file, the proven methodology can now be used on more current files as they are made available. However, it is important to be aware of the limitations of the resulting data set, in particular the fact that it cannot be used for tracking individual cases.

Examples of ways the database is currently being used include:

- 1) Initial study of adverse outcomes of obstetrics services in rural areas where pregnancy complications seem to require higher levels of hospital care than would be needed if Level I hospitals were available. Findings indicate that outcomes are worse in certain rural areas where no Level I hospitals exist because patients delay admission, entering Level II hospitals later and must be transferred to Level III hospitals due to complications rather than receiving care earlier in a Level I hospital. The study uses state defined rural hospitals and zip code clusters that match hospital locations.

2) Survey of pediatricians, general practitioners, nurse practitioners providing pediatric care to see who is providing care in rural areas and study the first year risk of rehospitalization of infants after birth to see if any relationship exists between specific conditions, health care plans, or supply of providers.

3) As part of a federal Office of Rural Health Policy funded study of Deregonalization of Managed Care, will examine baby transfers to inappropriate level of hospital to determine if a delay exists in providing treatment due to cost savings incentives or contractual restrictions on transfers. Answer the question: If you belong to an HMO, is your baby more or less likely to be transferred to the wrong "level of care" hospital (Level I, II, III)?

4) Study zip codes and type of care provided to "unsponsored" births not accounted for under the AIM program which pays for unsponsored births up to 300% of poverty (Medi-Cal only pays up to 200% of poverty). Approximately 12,000 to 30,000 births are accounted for under the AIM program at a cost of \$200M. By isolating the known AIM and Medi-Cal births, clues may arise that indicate where and why the remaining "unsponsored" births take place, whether they get prenatal care, and who is "unsponsored". A better understanding will help communities target outreach efforts through local hospitals, churches, and public health programs.

A public version of the database which strips out personal identifiers is currently being created and will be available on compact disk in approximately six to eight weeks. For more information about the above database or how to obtain the file on Compact Disk when it is available, please contact CHIPP at (916) 324-0051 or email us at chipp@oshpd.cahwnet.gov.

NEW INVENTORY OF CALIFORNIA DATABASES - AVAILABLE SOON

A second, more comprehensive inventory of over 100 databases held by California Health and Welfare Agency departments is near completion and will be available on diskette or you can find it live on the Internet from our web site at <http://www.chipp.cahwnet.gov> in approximately 30 days.

The new version is more versatile than the first edition, and includes key word and categorical searching, narrative descriptions, and listings by department. The name and phone number for a contact person is included. Copies of this software will be available at no cost on diskette or through file transfer from the CHIPP web page at <http://www.chipp.cahwnet.gov> or email at chipp@oshpd.cahwnet.gov.

CALIFORNIA FACT BOOK ON HEALTH PUBLICATION

A new publication produced jointly by the Office of Statewide Health Planning and Development and CHIPP will be released in December and available after December 15, 1996 on the CHIPP web page for downloading or viewing in PDF (Portable Document Format) using the free Acrobat Reader application. It can also be requested on diskette by contacting CHIPP email (chipp@oshpd.cahwnet.gov) or by telephone at (916) 324-0051 for those who do not have access to the Internet. The Fact Book makes generous use of multi-color charts accompanied by narratives to display comprehensive information about California's population, health status (births, immunizations, deaths, aids, heart disease, cancer), health financing, health resources, and utilization patterns.

RURAL JOB RECRUITMENT WEB PAGE

During the past year, CHIPP assisted the Health and Welfare Agency's Rural Health Policy Council with development of a new web page for health care related job recruitment in California's rural areas. The site currently contains 59 job listings and is searchable by region, practice setting, and type of position. When you visit the site it also links with the National Rural Health Job Recruitment site which acts as a central referral point for other state web sites and offices with rural job recruitment programs. The new site is located at <http://www.ruraljob.cahwnet.gov/> or can be reached from CHIPP's web site.

SEMINARS TO BE OFFERED BY CHIPP

CHIPP is planning to sponsor a series of half day executive training seminars that will help policy makers and program managers to:

separate the "wheat from the chaff" when evaluating voluminous information

match critical health care issues with appropriate information resources

gather complete information about the issue at hand

evaluate highly condensed information using fundamental measures for quality, access, effectiveness, efficiency, and cost

network and collaborate with peers

The seminar offerings are currently targeted for Late Spring/Early Summer of 1997 and will be announced on the CHIPP web site as the final curriculum is developed. Please stay tuned for more information.

OTHER IMPORTANT NEWS

The Department of Health Services (DHS) recently adopted a policy to implement the collection of a common set of core data elements for all DHS health programs. Once collected, the core data will allow the DHS to use it to link records more accurately within a data base to get unduplicated counts over time and improve program management, and to link records across programs more accurately to improve case management, delivery of care, and program administration. CHIPP is working with DHS to tackle potential confidentiality and data security issues. The core data proposed for collection includes five primary data elements (birth name, birth date, birth place, gender, mother's first name) and seven confirmatory data elements (SSN, client number, father's name, mother's maiden name, alias or nickname, county of residence, zip code of residence). Prior to adopting a department wide policy on core data, the DHS Family Health Outcomes Project successfully demonstrated that using the core data provided a combination of high linkage rates, ease of collection, and the most data consistency. FHOP's work was presented by CHIPP to the National Committee on Vital and Health Statistics who is recommending it, along with other proposed identifiers, to the National Standards Board for consideration as an adopted national standard for identification. Other Health and Welfare Agency departments have expressed an interest in using the core data set in programs to improve upon the linkage problems caused by using social security numbers or client IDs as unique identifiers. CHIPP will continue to work with DHS during implementation and assist interested departments in this area over the next year.

UPDATE ON CONFIDENTIALITY AND PRIVACY LEGISLATION

STATE LEGISLATIVE SUMMARY:

SB 2132 - Solano County Integration of Human Services, Enrolled in Fall of 1996

Creates a four-year pilot program in Solano, Napa, Sutter and Yuba counties to give human services staff the ability to share information pertaining to clients.

History: In 1989, Solano county began consolidating human service departments into one Health and Social Services Department to comprehensively support human service needs and increase efficiency and effectiveness of providing human services. Because of inter-related service needs, programs began making referrals to other programs and needed to exchange information. Current confidentiality statutes limit data sharing in various areas of human services. Although consolidated organizationally, staff remained bound by program specific statutes created prior to consolidation that precluded data sharing without proper authorization.

Certain spot legislative relief broadened authority for specified purposes, such as AB2184 (1991) allowing data sharing for children's multi-disciplinary service teams, and pilot programs developed by the Solano county for elderly, disabled, and neighborhood populations. However, current confidentiality regulations and rigid interpretations of various human service programs make the sharing of personal data cumbersome. SB2132 provides for:

- Data sharing between Public Health, Mental Health, Adult Services, Child Welfare, AFDC, General Assistance, Medi-Cal, Family Health, Substance Abuse, Employment Services, and the Public Guardian programs.
- Client to provide informed consent in writing before participating.
- Creation of a central case record system to include name, address, age, SSN, medical coverage, eligibility data, and services data accessible to county staff and staff under contract with the county.
- prohibitions against unauthorized release of information with penalties as set forth under current law.

SB 1659 Personal Rights/Privacy, Enrolled in Fall of 1996

Creates Joint Task Force on Personal Information and Privacy to recommend changes in law needed to better protect the constitutional right to privacy in light of advancements in information technology. SB1659 legislation:

- establishes a Joint Task Force on Personal Information and Privacy comprised of three members of the Senate and three members of the Assembly.
- specifies task force to recommend laws related to the use or distribution of personal information about individuals by public and private entities, to ensure state law adequately protects the right of privacy under the State Constitution, and adequately addresses the issues raised by the changing nature of information technology and systems.
- Directs issues addressed to include but not be limited to 1) the direct marketing industry, 2) the Internet industry, 3) the finance and credit industries, 4) the use of medical records, 5) the use and distribution of public records kept by state and local government agencies, 6) mechanisms in place to enforce privacy laws, including the issues raised by the past defunding of the Office of Information Practices.
- Specifies consultation with an advisory committee, comprised of an equal number of industry and consumer representatives as defined.
- Directs the Legislative Analyst's Office to compile the task force findings and recommendations into a report by March 1, 1998. Appropriates \$75,000 from the General Fund to LAO to carry out.

AB 3013 Medical Malpractice/Informed Consent/Unconscionable Contracts (Alby) Enrolled Fall 1996

This bill would eliminate "gag" or "confidentiality" clauses in provider plans in order to ensure that physicians have the freedom to appropriately communicate with the advocate for their patients. Under current case law, it appears a physician has a duty to provide full disclosure as to alternative methods of treatment and all the potential benefits and risks involved with each, as well as to refer the patient out to specialists if that is appropriate in the physician's judgement. A patient's consent to medical treatment, to be effective, must be an informed consent, and the patient must rely, with total dependence and trust, on the physician for the information necessary

to give informed consent. As an integral part of the physician's overall obligation to the patient, there is a duty of reasonable disclosure of available choices with respect to proposed therapy and inherent dangers. Failure by a physician to meet these standards would clearly subject the physician to potential liability for negligence, battery or malpractice.

This bill specifically permits communications regarding treatment options but precludes a provider from soliciting for alternative coverage arrangements for the primary purpose of securing financial gain.

AB 254 Immunization Registry System - Chaptered 1995/96.

Existing law requires children to receive certain immunizations prior to admission into school or licensed child care programs; requires the county to operate programs designed to make immunizations available; requires the state to adopt and enforce regulations to carry out immunization; and intends for the State to achieve total immunization against preventable childhood diseases.

This bill states legislative findings regarding the need for immunizations and the extent of/or need for better compliance, authorizes counties to operate immunization registry systems, and allows providers to share specified information from a patient's medical record with county health departments and the state Department of Health Services. The information includes: name, birth date, immunization data, address, telephone number, gender, birth place, and other information necessary to establish the patient's identity. AB 254:

- Requires county health and DHS to maintain the confidentiality of the shared information as they do for other patient-specific medical information.
- Allows the shared information to be used only to provide immunization services and reminder notices, to facilitate third party payment, and to provide statistical information about groups or populations without patient-identifying information.
- Requires providers to inform patient/parent that information may be shared, treated confidentially as allowed, and that consent to allow the provider to share the information with the county or DHS may be refused.
- Allows county health department to share the immunization information with other local health departments, other health care providers caring for the patient, school officials and licensed child care providers.
- Makes inapplicable the requirement that DHS adopt and enforce regulations concerning this specific subject.

Similar bill was defeated in prior year because it made no provision for a person to refuse to release personal information. This bill provides for consent of patient/parent to allow provider to share personal information with the local health department and/or the State.

FEDERAL LEGISLATIVE SUMMARY:

S. 1360 The Medical Records Confidentiality Act (Bennett-Leahy bill)

Remains stalled. The Senate Labor and human Resources Committee indefinitely delayed mark-up of the bill due to opposition from a number of industry groups. Objective is to establish rules in Federal law governing access to and disclosure of identifiable health information as well as penalties for unauthorized disclosure. The bill would give individuals the right to have access to health information about themselves, but would place restrictions on the ability of others to acquire identifiable health information typically held by providers or institutions.

HR 3482 The Medical Privacy in the Age of New Technologies Act (McDermott) Pending. Similar to S.1360 in objective and overall approach but includes a number of restrictions on access to information for research purposes by far in excess of current regulations or S.1360.

HR 1271 Family Privacy Protection Act - Pending. Leftover from Contract with America, bill already endorsed by House and ready for floor action in the Senate. Would require written parental consent before minors could participate in surveys on certain sensitive topics. Affects health research.

HR 3103 Health Insurance Portability and Accountability Act of 1996 (Kennedy-Kassebaum) Passed 1996, effective July 1, 1997.

Limits insurance companies' ability to discriminate against persons with health problems. HR3103 provides for:

- Pre-existing condition exclusions
- Small group protections which allow insurability regardless of rating
- Guaranteed individual coverage offered to those losing group coverage
- Non-discrimination and guaranteed renewability
- Benefits to children and pregnant women
- Electronic transfer of medical records

Section described as "administrative simplification" mandates:

- the development and adoption of standards for electronic exchange of health information.
- development of standards for a unique health identifier for each individual, employer health plan, and health care provider
- develop security standards for health information
- develop safeguards that require those who maintain or transmit health information to adopt reasonable and appropriate administrative, technical, and physical safeguards that will protect the integrity and confidentiality, and protect against unauthorized uses and disclosures of health information.
- requires covered entities to comply with standards within 24 months of adoption

Section on privacy provisions mandates:

- within 12 months of enactment, HHS must submit a report to Congress on the privacy of individually identifiable health information. The report must address the rights individuals should have with respect to such information, the procedures that should be established for exercising these rights, and the uses and disclosures of information that should be authorized or required.
- Within 36 months of passage, Congress must enact legislation protecting the privacy of health information in standards for electronic exchange.
- If Congress fails to enact privacy legislation within 36 months, HHS must promulgate final regulations protecting the privacy of health information in standards for electronic exchange within the following six months.
- maintains existing state confidentiality statutes that are stronger than those enacted by Congress or promulgated by HHS.

- Establishes criminal and civil penalties (fine not more than \$50,000 and imprisonment not greater than 1 year) for those who knowingly and in violation of the act misuse unique health identifiers, obtain individually identifiable health information, or disclose individually identifiable health information.